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Addressing dementia with Indigenous peoples: a contributing initiative from the Circular Head Aboriginal community

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A major public health issue in Australia is the continuing health inequality between Indigenous (Aboriginal and Torres Strait Islander peoples) and non-Indigenous Australians, and the urgent need to close this gap.¹⁻³ A key component of this health disparity is the notably higher prevalence rates of dementia now documented for younger as well as older Indigenous Australians, and increasingly men as well as women.^{2,4-8} This growing burden of disease has been proposed to reflect complex and intergenerational health risk factors. Studies document how Australia's Indigenous peoples are at greater risk for chronic diseases that increase susceptibility to dementia, including Type 2 diabetes, cardiovascular disease and obesity. This is compounded by the consequences of repeated head injury, depression, physical inactivity, smoking, substance abuse, limited education, and loss of social and cultural connectivity.^{2,9-15} An additional factor, recently identified, is the impact of childhood stress on emotional health and dementia in later life.¹⁶ Further, there is increasing understanding of Indigenous peoples' vulnerability to vascular brain damage, particularly damage deep in the brain.¹⁷ The resulting cognitive impairment is characterised by disturbances in frontal-executive functions, complex attention and processing speed, and changes in behaviour and emotion, rather than memory loss, but may co-exist with Alzheimer-type changes in function.¹⁷

Effective and sustainable strategies to address these potentially modifiable health risk factors and decrease vulnerability to dementia must recognise the strengths, history, cultural and linguistic diversity, and role of Elders in each Indigenous community. Further, effective strategies need to be based upon each community's understanding of

dementia and suggestions for culturally appropriate education about how to prevent and modify these risks, access culturally safe healthcare services, counter discrimination and stigma, and provide within-community care.^{7,9,18-22}

Published studies, although few, document valuable descriptions of the behaviours and psychiatric symptoms associated with dementia by mainland and Torres Strait Islander Indigenous peoples. However, these studies also illustrate Indigenous peoples' limited understanding of how such behaviours and symptoms relate to dementia, the causes of dementia, and how dementia differs from depression, delirium and other neurological diseases.^{7,23-25} The studies confirm the importance of community-based education and care provided by trusted, accepted and qualified Indigenous staff.^{21,22}

To date, there are no systematic data from Indigenous communities in Tasmania regarding their understanding of dementia and needs for education, care and risk modification. This 'data desert'²⁶ adversely affects the health of each community and the delivery of services to Indigenous peoples with dementia, as well as the advocacy and related work of health professionals, researchers and legislators.

The Circular Head Aboriginal Corporation (CHAC) in Smithton, the community heart of the North West nation, has initiated a partnership with researchers at the University of Tasmania to address its concern about dementia, particularly from an intergenerational perspective. CHAC community leaders seek to emphasise the need for young as well as older people to understand risk factors that may be modifiable and to promote overall health. This partnership represents CHAC's ongoing

development as a supporting, caring community organisation empowering the Aboriginal community of Circular Head to self-determination and self-sufficiency. This enables control of and responsibility for community health and wellbeing. In this Aboriginal community, there are four specific health promotion sites²⁷ in which general health and dementia risk reduction strategies can be sustained across the life span to promote quality of life. These four sites are: i) the Circular Head Aboriginal community health centre; ii) the Men's Shed and related programs at Trawmanna (a First Peoples' Land grant); iii) the Smithton High School; and iv) Emmerton Park, the local residential aged care community. At a weekly luncheon in a meeting space celebrating the work of a community Elder, older participants reported that, "Better understanding and awareness of dementia would give us a better quality of life knowing that we are not alone. Involving us in social support groups would help us gain and strengthen relationships, which in turn would be a great health outcome".

As an initial step to address concerns raised by CHAC leaders about the growing impact of dementia on community members – both young and older – and their family carers, 50 volunteer members met in a series of listening and yarning sessions based on community-led approaches to data collection.^{5,18-20,24,25}

These sessions gathered information to guide future community-based training and education. The 38 women and 12 men who participated ranged in age from 22 to 85 years ($M = 46.4 \pm 16$). They represented a variety of educational qualifications, occupations and employment settings. Only four reported they had received any formal education regarding dementia risk and care.²⁸ In the sessions, participants completed the 27-item Dementia Knowledge Assessment Scale (DKAS) developed by researchers at the Wicking Dementia Research and Education Centre,^{29,30} and 12 participants shared their dementia care experiences in individual follow-up interviews.²⁸ The DKAS, rather than the modified Alzheimer's Disease Knowledge Test,²³ was chosen as it has a global focus on dementia, including vascular health, which is of particular relevance to Indigenous peoples.^{7,8,17}

The 27 items on the DKAS asked respondents to use a Likert scale (false, probably false,

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true, probably true, don't know) to answer questions about the causes, characteristics, and types of dementia, risk factors for dementia, and care needs. Correct answers received two points, 'probably correct' answers received one point, and 'probably incorrect', 'incorrect' and 'don't know' responses received no points. The maximum attainable correct score was 54.^{29,30} In completing the DKAS, respondents also had the opportunity to relate and/or document their experience in caring for people with dementia.

This is the first known report about Indigenous peoples' response to the DKAS. Community leaders reviewed the scale and advised against changing the wording of items for this initial study. Participants completed it in communal sessions where they were able to ask for clarification of terms as needed. Notably, one out of every four participants stated they had provided, or were providing, care for people living with dementia; three out of every four reported limited knowledge about dementia and little confidence in their ability to provide effective care. The mean DKAS score for the 50 participants was 27.73/54. Understanding correct responses for only half (50%) of

the DKAS items suggests relatively low overall dementia knowledge in this cohort. However, mean dementia knowledge scores for non-Indigenous groups, as measured using the DKAS and other tools, are not substantially higher.^{30,31} Annear and colleagues³⁰ analysed DKAS responses from a group of 3,649 Australian and international participants, including health professionals, students and members of the general public. Indigenous and ethnic data were not gathered or reported. Mean scores ranged from 34.46 (family carers) to 37.89 (nurses). In a study of 1,000 participants, aged 20–75 years, investigating their intention to change dementia risk behaviours, Smith and colleagues³¹ conducted a 10-minute telephone survey. Survey questions were taken from previously published studies. Dementia knowledge was measured by participants rating their agreement, using a five-point Likert scale, with the statement that it is possible to reduce the risk of a person developing dementia. Participants who responded affirmatively were then asked to provide up to five responses as to how dementia risk could be reduced. Indigenous and ethnic data were not reported. Of the 1,000 participants, 44.5% were scored as having low dementia knowledge. This finding

was associated with less likelihood to change dementia risk behaviours.

What is of particular interest and importance in the responses of members of the Circular Head Aboriginal community is an examination of the 11 DKAS items on which the 50 community members scored most poorly. These 11 items (and evidence as to whether each is currently True, False, or increasingly possible) are listed in Table 1. They illustrate the limited understanding of these community members about dementia and known modifiable risk factors. This is a valuable finding as it sets the stage for continued community-led discussions as to how community health can best be promoted and vulnerability to the risk of dementia decreased.

In the follow-up interviews, community members provided rich insights into their lived experiences with dementia care. They drew on cultural metaphors to give meaning to dementia in terms of family members 'fading away' and of carers 'covering up' and 'hiding' dementia symptoms. In line with published findings from other Australian Indigenous communities, concerns centred on the need to have members of the community receive within-community training to become qualified to provide culturally appropriate dementia care and facilitate culturally-based education about dementia and modifiable risk factors.

The needs expressed by this cohort of the Circular Head Aboriginal community leaders and members are consistent with targeted strategies towards 'closing the gap' in Indigenous health inequalities¹ and the public health approach to dementia advocated by the World Health Organization.³² The data document several important issues. The first is the reported increasing number of people with dementia in this Aboriginal community and their needs for care. The second is the limited confidence and capacity of community members who provide care. The third is the need for community members who are trained and qualified to provide dementia education and culturally appropriate, evidence-based care. The data illustrate the importance of a public health partnership methodology where CHAC leaders identified dementia as a community concern, shared practical experience, co-developed the research design in line with community needs, facilitated recruitment and data collection, and evaluated the results in partnership with the research team. The data

Table 1: Mean item scores (out of a maximum score of 2) for the 11 DKAS items on which the 50 community members scored most poorly, in ranked order.

DKAS item	Correct Response	Mean Item Score (max 2)
Maintaining a healthy lifestyle does not reduce the risk of developing the most common forms of dementia	False	0.92
Alzheimer's disease is the most common form of dementia	True	0.90
	along with increasing recognition of the impact of vascular dementia, particularly for Indigenous people	
Medications are the most effective way of treating behavioural symptoms of dementia	False	0.84
An early diagnosis or recognition of dementia does not generally improve quality of life for people experiencing the condition	False	0.80
Symptoms of depression can be mistaken for symptoms of dementia	True	0.79
Most forms of dementia reduce the length of a person's life ^a	True	0.74
A person experiencing advanced dementia will not generally respond to changes in his/her physical environment	False	0.71
Most forms of dementia do not generally shorten a person's life ^a	False	0.66
Blood vessel disease (vascular dementia) is the most common form of dementia	False	0.45
	but increasingly possible and particularly relevant to First Nations people	
Having high blood pressure increases a person's risk of developing dementia	True	0.41
The sudden onset of cognitive problems is characteristic of common forms of dementia	False	0.32
Total		7.54 of the cohort's overall mean score of 27.73/54

Notes:

a: These two items question the issue from affirmative and negative positions

have provided the foundation for a successful application by CHAC/UTAS researchers to the Department of Health/Dementia and Aged Care Services (DACS) for Aboriginal members of this community to undertake an innovative and within-community University and TAFE partnership program in community-driven dementia education and care.³³ Twelve students (high school leavers to mature age) are now completing a Certificate III program in Individual Support (Ageing, Home and Community) in their community, while also undertaking two units per semester in the award-winning online Bachelor of Dementia Care, developed by the Wicking Centre. Results of this two-year public health initiative (2017–2019) will contribute to the education, health and wellbeing needs identified by this Aboriginal community, and may serve as a model for other Indigenous communities dealing with dementia.

Conclusion

This paper details the public health initiative driven by the Circular Head Aboriginal community that identified the community's understandings of dementia and suggestions for culturally appropriate and community-based education. This education includes the modification of dementia risks and innovative ways in which to develop a skilled Aboriginal workforce to improve the intergenerational health and wellbeing of this community.

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